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ABSTRACT

The operations and effectiveness of the Centers for Disease Control's (CDC) human immunodeficiency virus (HIV) counseling and testing programs were reviewed. CDC officials were interviewed; documents pertaining to CDC counseling and testing programs were obtained; and public health departments receiving CDC funds in Colorado, Massachusetts, New Hampshire, Virginia, New York City, and San Francisco were visited. Policies and procedures for performing HIV counseling and testing were reviewed at these locations and records kept on program operations were examined. Sixteen counseling and testing sites funded by the grantees were visited. The literature on counseling and testing programs was reviewed, the Acquired Immune Deficiency Syndrome (AIDS) Counseling and Testing Act of 1988 was analyzed, and AIDS advocacy groups were met with to obtain their views. Based on this review and analysis of federal counseling and testing legislation debated during the 100th Congress, five salient issues were identified: (1) oversight and evaluation of grantee performance; (2) outreach to intravenous drug users; (3) follow-up and long-term counseling; (4) implementation of partner notification; and (5) antidiscrimination protection for persons infected with HIV. Preliminary findings on these issues should facilitate Congressional oversight and deliberations on federal HIV policy. (NB)

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Report to the Chairman, Committee on Governmental Affairs, U.S. Senate

February 1989

AIDS EDUCATION

Issues Affecting Counseling and Testing Programs

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Human Resources Division

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February 3, 1989

The Honorable John Glenn
Chairman, Committee on
Governmental Affairs
United States Senate

Dear Mr. Chairman:

This report responds in part to your request of September 26, 1988, concerning federal and state education programs to prevent the spread of the human immunodeficiency virus (HIV), which causes acquired immunodeficiency syndrome (AIDS). Since neither a vaccine nor cure has been developed, education is necessary to control the HIV epidemic, which many experts regard as the most serious public health threat of this century. In fiscal year 1989, the Centers for Disease Control (CDC), an agency in the Department of Health and Human Services (HHS), will increase health department funding to about $95 million for an important part of its education strategy—voluntary HIV counseling and testing programs.

Acknowledging the growth and importance of counseling and testing programs, the House of Representatives passed comprehensive legislation regarding these programs during the 100th Congress. If enacted, it would have authorized a 3-year, $1.2 billion grant program to expand counseling and testing services. According to a House Committee on Energy and Commerce report,[1] the legislation established a framework for delivering services that reflected universal recommendations of public health authorities. It also attempted to reduce significant disincentives to program participation by assuring the confidentiality of medical records across all states.

The law that subsequently passed—the Health Omnibus Programs Extension of 1988 (P.L. 100-607)—was signed by the President on November 4, 1988. Title II (Programs with Respect to Acquired Immune Deficiency Syndrome) of the law authorized (1) $200 million ($100 million for each of fiscal years 1989 and 1990) for sites that provide anonymous counseling and testing services and (2) 780 additional employees for the Public Health Service to conduct its AIDS activities. Within 90 days from enactment, the Secretary of HHS is to report to the Congress

[1]The Committee report accompanied the AIDS Counseling and Testing Act of 1988 (H.R. 4757), which was later passed by the House as part of the AIDS Federal Policy Act (H.R. 5142).

on his allocation of these employees. The act was silent on most other counseling and testing issues in the House bill.

Based on our review to date and our analysis of federal counseling and testing legislation debated during the 100th Congress, we identified five salient issues that bear on mitigating the impact of the HIV epidemic. These are

- oversight and evaluation,
- outreach to intravenous drug users,
- follow-up and long-term counseling,
- partner notification, and
- antidiscrimination protection.

At your request, we are reporting our preliminary observations on these issues to facilitate congressional oversight and deliberations on federal HIV policy. You also asked us to continue our review of counseling and testing programs to further clarify the significance of these issues and develop potential solutions to problems we identify at the federal, state, and local levels.

Background

CDC is responsible for controlling the introduction and spread of infectious diseases. It also monitors communicable diseases, environmental health hazards, and other public health problems. The states report cases of diseases, such as measles, tuberculosis, and rabies, to CDC, which publishes and disseminates these data on a weekly basis and, if necessary, steps in with measures to control the spread of outbreaks. In 1983, CDC added AIDS to its list of reportable diseases.

As of January 9, 1989, there were over 83,000 cumulative cases of AIDS reported to CDC, and more than 46,000 Americans had died of the disease. The Public Health Service predicts the AIDS toll will rise to 365,000 cumulative cases and 263,000 deaths by the end of 1992. In addition, other HIV-related diseases will cause significant morbidity and mortality.

Because HIV is sexually transmitted, CDC assigned responsibility for preventing HIV infection to the Sexually Transmitted Disease Division of the Center for Prevention Services (CPS). In addition to its AIDS prevention work, the Center funds activities of clinics that provide treatment to walk-in clients for diseases such as syphilis, gonorrhea, herpes, and chlamydia.

An important part of CDC's strategy to educate persons about risk reduction has been antibody testing and adjunct counseling directed at those at greatest risk of exposure to HIV.[2] Between 1985 and 1988, CDC awarded nearly $120 million for counseling and testing services and will increase funding for these services in fiscal year 1989 to about $95 million—about 26 percent of its AIDS funds.

The fiscal year 1989 funds will be available to 63 state, local, and territorial health departments through cooperative agreements. The health departments receive on average about $1.5 million each, and, in turn, use funds to support activities at the actual counseling and testing sites. CDC provides general guidance to health departments through program announcements and nonmandatory guidelines,[3] while health department grantees are responsible for program management and oversight of the sites. CDC is also responsible for ensuring overall program effectiveness through oversight, monitoring, technical assistance, and evaluation.

Through its grantees, CDC has funded two types of counseling and testing sites. First, in 1985, CDC supported sites set up solely to provide counseling and testing for HIV. Commonly called alternate test sites, they provided wider access to the antibody test at locations other than blood banks, which used the test to screen donated blood. Public health officials were concerned that without these alternate test sites, persons who feared they had been exposed to HIV might seek to donate blood to find out their antibody status. At state discretion, services at these sites are provided on either a confidential or anonymous basis.[4]

In 1986, CDC broadened the HIV program by recommending that other types of public health facilities that receive federal funds routinely offer counseling and testing services to persons likely to be at increased risk of infection. Many opportunities to educate homosexual and bisexual men, intravenous drug users and their sexual and needle-sharing

[2]In response to HIV infection, the immune system produces antibodies that are detectable through a blood test. Antibody status is positive if HIV antibodies are identified in the blood, and negative if testing reveals no HIV antibodies.

[3]Centers for Disease Control, "Additional Recommendations to Reduce Sexual and Drug Abuse-Related Transmission of Human T-Lymphotropic Virus Type III/Lymphadenopathy-Associated Virus," Morbidity and Mortality Weekly Report, Vol. 35, No. 10, Atlanta, Mar. 14, 1986, pp. 152-55 and "Public Health Service Guidelines for Counseling and Antibody Testing to Prevent HIV Infection and AIDS," Morbidity and Mortality Weekly Report, Vol. 36, No. 31, Atlanta, Aug. 14, 1987, pp. 509-15.

[4]Under a confidential testing system, the patient may provide a name or pseudonym and medical records are kept confidential, in accordance with state law. In contrast, patients tested at anonymous test sites do not reveal their names but instead are given code number identifiers.

partners, and others at increased risk exist in these settings. CDC specifically encouraged counseling and testing for patients served in facilities receiving federal funds, including (1) sexually transmitted disease clinics, (2) drug treatment centers, and (3) family planning and prenatal care clinics. Also, CDC has recommended that tuberculosis clinics conduct HIV counseling and testing because of the recent increase in tuberculosis and its correlation with HIV infection.

Based on years of experience with sexually transmitted disease control programs, CDC believes that persons informed of their infection are more likely to modify their risky behavior than those who remain unaware. Moreover, according to an Office of Technology Assessment report, face-to-face interventions show promise and merit further study along with other education techniques.

We testified in June 1988 that much more remains to be learned about how to motivate long-term changes in the sexual and drug-using behaviors that spread HIV.[5] Consequently, we expect some false starts yet view unsuccessful efforts as the unavoidable price of rapidly implementing new education strategies. More recent research shows that so far neither public sector organizations nor private sector foundations providing HIV education have done much to find out about the effects of their programs. Faced with methodological difficulties, limited resources, and the urgency of controlling the epidemic, early education programs skimped on evaluation. As a result, information about the effectiveness of public and private programs has accumulated slowly. In our testimony, we concluded that the federal government should take the lead in conducting rudimentary studies that begin to identify what does and does not work. Generally tight budgets and the continuing need to slow the spread of HIV heighten the importance of understanding the effectiveness of counseling and other education programs.

Objectives, Scope, and Methodology

At your request, we are currently reviewing the operations and effectiveness of CDC's HIV counseling and testing programs. To facilitate congressional oversight and deliberations on these programs, you asked that we report our preliminary observations based on work at CDC and in selected states. We plan to evaluate further the effects of the following five issues on the ability of CDC and its grantees to control the spread of HIV:

[5]U.S. General Accounting Office, Issues Concerning CDC's AIDS Education Programs, GAO/T-HRD-88-18, Washington, D.C., June 8, 1988.

- oversight, monitoring, and evaluation of grantee performance;
- outreach to intravenous drug users;
- follow-up and long-term counseling;
- partner notification; and
- protection from discrimination for individuals with HIV infection or AIDS.

In the course of our work to date, we interviewed CDC officials in Atlanta, Georgia, and obtained relevant documents pertaining to the agency's counseling and testing programs. We also visited public health departments receiving CDC funds in four states—Colorado, Massachusetts, New Hampshire, and Virginia; and two cities—New York City and San Francisco. At health departments in these locations, we reviewed the policies and procedures for performing HIV counseling and testing and examined records kept on program operations. We also visited 16 counseling and testing sites funded by the grantees. Finally, we reviewed the literature on counseling and testing programs (see bibliography), analyzed the AIDS Counseling and Testing Act of 1988, and met with AIDS advocacy groups to obtain their views.

We did our work between November 1987 and October 1988. At your request, we did not obtain formal agency comments on this report. We did, however, obtain views of agency officials at the federal, state, and local levels and incorporated their views where appropriate.

Oversight and Evaluation of Grantee Performance

Our work at CDC indicates that staff shortages in the Center for Prevention Services and lack of sufficient program data have hampered efforts to provide technical assistance and evaluate the performance of counseling and testing grantees. Without adequate program information and evaluation, CDC will have limited ability to identify programs that work better and redirect programs that may be using less effective strategies. The Secretary can help remedy this situation by allocating additional staff to CPS from the recent authorization of 780 employees for the Public Health Service's AIDS activities.

Our work to date indicates that CPS has not adequately monitored and evaluated its AIDS counseling and testing grantees.[1] CPS staff are expected to advise the departments on how to develop and operate AIDS

[1]In our June 1988 testimony, we attributed insufficient monitoring of grantees to the excessive workloads of the nine project officers at CPS who had been assigned to AIDS education. CDC officials told us that by January 1989, they had increased the number of project officers to 18, which CDC deems adequate for monitoring of grantees at the present time.

education programs, conduct program evaluation reviews, and monitor state and local health department progress.

CDC officials told us that the ability of states and local communities to effectively use federal AIDS funds for counseling and testing requires more on-site technical assistance. CPS has not had enough behavioral science specialists, however, to serve as technical advisors to counseling and testing grantees. In particular, trained counselors have been needed to integrate HIV counseling and testing at drug treatment centers. Staff shortages have also contributed to insufficient evaluation of counseling and testing programs, an essential component of technical assistance according to CDC program requirements.

Sound program management also requires consistent and reliable program information to measure and compare grantee performance. However, it was not until July 1988—3 years after the first federal AIDS education funds were awarded—that CDC obtained approval from the Office of Management and Budget to require grantees to submit consistent risk group and demographic data. According to CDC officials, the agency will not have a sufficient database for 2 years, although these data are needed to set objectives and evaluate basic program outcomes. For example, grantees must know how to modify their programs, if necessary, to reach those at greatest risk of infection. Our preliminary observations indicate that counseling and testing programs in some areas may serve more low-risk heterosexuals who are healthy but worried than high-risk homosexual and bisexual men, intravenous drug users, and their sexual and needle-sharing partners.

Outreach to Intravenous Drug Users

Public health experts agree that intravenous drug users pose a significant threat to expansion of the HIV epidemic among heterosexuals. Reflecting this, CDC recommended in its 1986 guidelines that grantees initiate outreach programs and routinely counsel and test all persons seeking drug treatment or having a history of intravenous drug abuse. State officials told us that lack of resources and staff reluctance to become involved with HIV-infected persons had slowed implementation of counseling and testing at drug abuse clinics.

The six health departments we visited, for example, had generally not undertaken outreach initiatives. Consequently, of those tested in these six locations, 7.4 percent were intravenous drug users. Nationally, however, intravenous drug users presently constitute about 34 percent of the AIDS cases. In addition, none of the six health departments we visited

routinely offered federally funded HIV testing in drug-free treatment programs, detoxification centers, drug shelters, halfway houses, or prisons. The availability of HIV services at methadone clinics varied. One grantee routinely offered HIV services to intravenous drug users at about one-fourth of its methadone maintenance clinics, one did not have a publicly funded methadone clinic, and four did not offer HIV services at their methadone clinics. As a result, opportunities to educate intravenous drug users about HIV infection were missed in these locations.

Follow-Up and Long-Term Counseling

Follow-up for clients not returning for test results and long-term counseling place time-consuming demands on staff resources.[7] These potentially expensive program components are considered important determinants of program success, however, especially for persons who may be difficult to reach or less receptive to education.

Our preliminary work indicates that the incidence of patient "no shows" can be especially high in sexually transmitted disease clinics because patients usually visit these clinics for treatment of specific ailments and must often be persuaded to accept HIV services. Specifically, about 57 percent of patients in one health department's sexually transmitted disease clinics and 70 percent in another's, did not keep their posttest counseling appointments. As a result, people who are infected, or noninfected but engaging in risky behavior, may neither be advised nor counseled on the precautions they should take to avoid spreading or contracting HIV infection.

At the time of our review, none of the grantees we visited had attempted to contact persons whose tests indicated they were not infected with HIV. Two grantees had attempted to contact infected persons who did not keep their follow-up appointments, but the others had not. These infected individuals pose a clear risk of transmission to others.

A growing body of evidence indicates that individuals who practice high-risk behaviors should be provided additional support services when necessary to encourage them to adopt safer sex practices or abstain from the use of contaminated needles. Longitudinal studies will be needed, however, to fully determine the effectiveness of these services on reducing risky behavior.

[7] Because counseling and testing sites send blood samples to laboratories for analysis, clients must return for test results and posttest counseling.

CDC guidelines state that HIV counseling and testing should always be linked with follow-up medical and psychosocial services. The single posttest counseling session most often provided is generally not sufficient to effect lasting behavioral change. This may be particularly important for infected individuals, intravenous drug users, and others who may not have support in their communities or who lack the resources for continuing care.

CDC officials cite studies that show periodically reinforcing education about risk reduction over time is important for sustained behavioral change. The potential value of continuing support is demonstrated by one of these studies indicating that one-third of infected individuals change their behavior, but then revert to high-risk activities when support stops.

Implementation of Partner Notification

Partner notification, a disease prevention tool used by public health authorities, is a highly confidential, integral part of programs to control sexually transmitted diseases, including HIV. CDC has recommended that all sexual and needle-sharing partners of HIV-infected persons be notified of their potential exposure, warned of the danger of exposure, encouraged to be tested, and educated about prevention measures and treatment options. Specifically, CDC suggests that HIV-infected persons be instructed on how to notify partners and refer them for counseling and testing. If HIV-infected persons cannot contact partners themselves, however, physicians and health department personnel should use confidential procedures to assure notification.

For years, CDC has used a form of partner notification called contact tracing to control the spread of sexually transmitted diseases, primarily syphilis and gonorrhea. Contact tracing uses trained epidemiologists to identify and notify as many sexual partners as possible about possible exposure. Perhaps more so than with other sexually transmitted diseases, however, HIV-infected persons run a significant risk of discrimination if their antibody status becomes known to employers, insurers, landlords, neighbors, or others who may perceive themselves to be at personal or financial risk.

Because of the stigma associated with HIV infection and the potential for discriminatory action, public health officials have modified partner notification procedures to balance threats to civil liberty and to the public health. Implementation of CDC's partner notification recommendations therefore varied in the health departments we visited. Some counselors

suggested that clients consider informing partners, while others routinely offered the assistance of health department personnel when clients were unwilling or incapable of notifying partners themselves. Of the six health departments we visited, one assigned health department staff to identify and contact partners, two provided health department assistance only if an infected individual asked for assistance, and the others only suggested that clients inform their partners.

Antidiscrimination Protection for Persons Infected With HIV

Although according to the Surgeon General HIV-infected persons do not pose a health risk to others in housing, the workplace, or other casual contact situations, there are no HIV-specific federal antidiscrimination protections for individuals seeking HIV counseling and testing. CDC officials believe this and variations in the states' confidentiality laws have limited the effectiveness of HIV counseling and testing programs. The potential consequences of a breach in confidentiality have a chilling effect on the willingness of at-risk persons to be tested. Fear of loss of employment and housing or denial of health insurance and medical services are powerful demotivators to those considering HIV counseling and testing.

GAO, the Office of Personnel Management, and some employers in the private sector have adopted workplace policies that explicitly allow HIV-infected employees to continue working. Two legal developments also offer protection for some persons with AIDS or HIV infection. First, section 504 of the Federal Rehabilitation Act of 1973 specifically proscribes discrimination against "otherwise qualified" disabled or handicapped individuals in programs or activities receiving federal funds.[8] A 1987 Supreme Court ruling held that a person with a communicable disease is legally handicapped and protected from discrimination under section 504. Prior and subsequent to the Supreme Court decision, lower courts have ruled that symptomatic AIDS is a handicap. Although several federal court decisions have suggested that HIV-infected persons without overt symptoms are protected under the statute, no cases have as yet so expressly held. Therefore, the legal situation of those who are infected with HIV but not showing overt symptoms of the disease is unclear.

In a September 1988 memorandum, the Justice Department endorsed the view that people infected with HIV are protected from discrimination

[8]The Civil Rights Restoration Act of 1987 replaced this "otherwise qualified" standard in the employment context with a slightly different statutory formulation that leads to a result substantively identical to that in the nonemployment context. That is, protection extends if the individual is able to perform the duties of the job and does not constitute a direct threat to the health or safety of others.

under section 504. Justice concluded that protection applied to people who showed symptoms of AIDS, as well as to those who had not developed symptoms but who carried the virus. This decision superseded Justice's previous position that discrimination based on fear of contagion was not prohibited by section 504.

Second, in the Fair Housing Amendments Act of 1988, the Congress extended protection from discrimination in housing to handicapped persons. Because the definition of handicap is the same as that used in the Rehabilitation Act of 1973, this had the effect of protecting HIV-infected persons in housing to the same extent as such persons are currently protected in programs and activities receiving federal funds.

In its 1988 report, the National Academy of Sciences' Institute of Medicine reported that "fear of discrimination is a major constraint to the wide acceptance of many potentially effective public health measures." Echoing this and drawing on extensive hearing records documenting the serious repercussions of discrimination related to epidemic control measures, the Presidential Commission on the Human Immunodeficiency Virus Epidemic recommended that the federal government take immediate, affirmative action to articulate a strong national policy against discrimination based on HIV infection. Both the Presidential Commission and the Institute of Medicine concluded that a federal law prohibiting discrimination is needed to improve the effectiveness of HIV education and other public health measures.

Federal antidiscrimination legislation could accomplish several objectives. First, it could extend protection to persons with AIDS in areas other than housing or programs and activities not receiving federal funds. Second, it could clarify the protection afforded HIV-infected persons not showing symptoms of AIDS. Finally, such legislation could also improve epidemic control efforts if providers of health services believe patient rights were better protected. For example, counseling and testing sites using anonymous procedures might switch to a confidential system, allowing them to collect demographic and other epidemiologic information needed to better control the spread of HIV infection.

As arranged with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 15 days from its issue date. At that time, we will send copies to other interested parties. A list of major contributors to this report is included as appendix I.

Sincerely yours,

Janet L. Shikles

Janet L. Shikles
Associate Director

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